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Demographic and social statistics: Washington Group on Disability Measurement

Report of the Washington Group on Disability Measurement

Note by the Secretary-General

In accordance with a request of the Statistical Commission at its thirty-third session,** the Secretary-General has the honour to transmit to the Statistical Commission the report of the Washington Group on Disability Statistics. The Commission may wish to (a) comment on the outcome of the first meeting of the Washington Group, and (b) to review the topics for future meetings of the Group.

* E/CN.3/2003/1.
** See *Official Records of the Economic and Social Council, 2002, Supplement No. 4* (E/2002/24, para. 1).

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I. Introduction

1. The Washington Group on Disability Measurement was established by the United Nations to enable the international community to address the themes and suggestions of the United Nations International Seminar on the Measurement of Disability. Its first meeting, hosted by the National Center for Health Statistics of the United States, was held from 18 to 20 February 2002 in Washington, D.C. The planning group for this meeting was comprised of representatives of Australia, the Statistical Office of the European Communities (Eurostat), Mexico, Uganda and the United States of America. Representatives from the national statistical offices of 30 countries and one United States commonwealth participated in the meeting. Eurostat, coordinating the European Statistical System, the World Health Organization and international organizations of people with disabilities, were also represented. In total, 58 persons participated in three days of sessions directed towards developing agreement on the nature of a global measure of disability to be recommended for use in censuses and surveys in the world community. The group also sought to develop an agenda for future meetings by prioritizing the most pressing issues in disability measurement and data collection.

2. The Washington Group reaffirmed the need for a city group to:

(a) Promote the regular collection and generation of statistical information on disability in populations by statistical offices around the world;

(b) Assist countries in the collection of disability information through censuses and within national statistical systems in the light of limited resources and competing demands regarding issues of national importance;

(c) Understand the role of statistical systems in providing information about disability to policy makers who are engaged in promoting full participation and improving the quality of life among people with disabilities.

II. Objectives

3. As the first order of business, the Washington Group examined the objectives established by the planning committee. At the completion of the sessions and discussions, the Group revisited the objectives and refined the wording to better represent the conclusions that had been reached. The following objectives were accepted enthusiastically by the participants and were used to guide the development of a work plan:

1. To guide the development of a small set(s) of general disability measures, suitable for use in censuses, sample based national surveys, or other statistical formats, which will provide basic necessary information on disability throughout the world.

2. To recommend one or more extended sets of survey items to measure disability or principles for their design, to be used as components of population surveys or as supplements to specialty surveys. These extended sets of survey items will be related to the general measures.

3. To address the methodological issues associated with the measurement of disability considered most pressing by Group participants.

4. Measures identified in objectives 1 and 2 will be culturally comparable to the extent possible. The International Classification of Functioning, Disability and Health (ICF) model, a useful framework to assist in the development of these measures, will be utilized in developing the measures.

III. Areas of agreement

5. The participants were in general agreement about the majority of the areas discussed. As one of the concluding activities of the meeting, participants reviewed a summary of the minutes and endorsed the following points:

(a) It is important and possible to craft internationally comparable general disability measures. Comparable general disability measure (or question) is a term to be used in place of the term "global measure" to reduce confusion about multiple meanings of the term "global";

(b) Given that there are multiple purposes for the use of a general disability measure, it may be necessary to develop multiple internationally comparable general measures relevant for several specific purposes;

(c) A short set of measures should be developed for use in censuses and surveys, and a longer set of measures (questions) should be cross-walked back to the short set of indicators;

(d) The agreed-upon minimum requirements for such a measure would be:

(i) A clear link of the purpose of measurement to the operationalization of the indicator(s);

(ii) A clear and specific definition of the aspect of "disability" to be measured;

(iii) Flexibility in translating an agreed upon reference document (that clearly outlines the concepts to be used, question wording and response categories) into multiple languages to allow the use of the appropriate terminology in each country;

(iv) A specification of the limitations of the general measures;

(v) A specification of how personal assistance or device use is treated in relation to the measure;

(e) An initial focus for an internationally comparable general indicator should be the activity dimension of ICF;

(f) The Washington Group should be concerned with:

(i) The provision of technical support for the development of internationally comparable general measure(s);

(ii) A research and testing program for indicator development;

(g) Census and survey questions for the indicators should avoid words with a negative connotation, such as "disability";

(h) Persons with disabilities should be included in the development of indicators;

(i) The development of working networks among participants and of a process through which technical assistance can be provided to countries with fewer resources is a high priority for an outcome of these meetings;

(j) A product of the first meeting of the Washington Group is a prioritized list of issues to be addressed at future meetings.

IV. Dissemination of results of the first meeting of the Washington Group

6. It was agreed that the results of the first Washington Group meeting would be disseminated by several methods. The Chairperson of the planning group for the first meeting presented a short report at the thirty-third session of the Statistical Commission. A full report on the meeting was posted on the web site (see http://www.cdc.gov/nchs/citygroup.htm) and provided to all the venues to which Group materials are customarily distributed. In addition, all presentations given at the meeting are available on the web site. Finally, materials from the Washington Group will be published in a special issue of *Research in Social Science and Disability*, a peer reviewed journal published by Elsevier publishers. The materials that will be included in this hardcover publication consist of a selection of papers based on presentations from the initial United Nations Seminar on Measurement of Disability, papers based on presentations at the first meeting of the Washington Group and the city group extended report.

V. Planning for future meetings

7. The first objective of the Washington Group is to provide a recommendation for a set of comparable general disability measures that can be used for various purposes. In order to accomplish that objective the following work needs to be accomplished:

(a) Completion of a matrix developed and agreed upon at the first meeting that matches the purpose of the proposed general measure(s), with conceptual definitions, items, reference questions and characteristics of questions, including such matters as whether duration is an important element of a given question;

(b) An evaluation of measures currently in use according to the dimensions of the matrix;

(c) A review of the results of methodological testing of general measures that have been done in various countries, including Canada, Australia and in Europe;

(d) If possible, one or two of the candidate general measures should be tested in several countries, particularly in developing countries, with results reported to the next meeting.

8. The second meeting will be held in Ottawa on 9 and 10 January 2003; 20 countries have confirmed attendance, in addition to representatives of international statistical organizations.

9. The first focus of the Ottawa meeting will be the finalizing of a matrix that cross-classifies the purpose that a general disability measure is supposed to address

(i.e., the use that the data will be put to) with a typology of question characteristics, such as the ICF domain, severity, duration, etiology and duration. A small working group, comprised of members from Italy, the United Nations and the United States, is currently developing the matrix. The cells of the conceptual version of the matrix describe the information for each characteristic that is needed to satisfy the specific purpose. In addition, an empirical version of the matrix is being developed that evaluates the characteristics of general measures currently in use according to the dimensions of the matrix. Those two matrices, detailing what we need to measure to fulfil purposes and what we have measured with existing general indicators, are intended to help the Washington Group to identify the gaps that exist in disability measurement and help direct future work in developing internationally comparable general measures of disability. A second area of discussion will focus on the presentation of results of current or planned research on disability measures. This will include the results of the 2001 Canadian Census and methodological work in Australia. In addition, a discussion of the participation and environment aspects of measuring disability will set the stage for future work.

10. A proposal was made for the subsequent meeting of the Washington Group to be held in Europe in fall 2003 in recognition of the European Year of People with Disabilities. The feasibility of that venue will be known in about two months. The planning group consists of members from the following countries or cooperative groups: Australia, Belgium, Brazil, Canada, Eurostat, Hungary, Italy, Netherlands, Poland, Uganda and the United States. The involvement of some countries mentioned here is subject to agreement of the national authorities concerned.

11. At the European meeting and future meetings, other objectives outlined by the Washington Group will be addressed. The second objective of the Washington Group will be to begin exploring and discussing sets of measures, related to the general measures, to be used as components in surveys. Questions addressing environmental factors and participation were of particular concern for exploration and discussion for another set of questions. A third objective is to focus on methodological issues. Two areas under consideration are special populations, in particular the collection of data associated with mental health problems and the use of administrative data alone or in conjunction with survey or census data. It was estimated that an additional three meetings would be needed to complete the work plan. It was also suggested that at each meeting, assessment of progress and decisions about continuation of work on any topic is necessary.